DOCUMENT RESUME

ED 165 077 CG 013 175

AUTHOR	Minde, K.; And Others
TITLE	Self-Help Groups in a Premature Nursery: A Controlled Evaluation.
SPONS AGENCY	Department of National Health and Welfare, Ottawa (Ontario).; Laidlaw Foundation, Peoria, Ill.
PUB DATE	78
GRANT	606-1360-44A1
NOTE	25p.; Paper presented at the Annual Meeting of the American Orthopsychiatric Association (55th, San Francisco, California, March 27-31, 1978)
AVAILABLE FROM	K. Minde, Department of Psychiatry, The Hospital for Sick Children, 555 University Ave., Toronto, Ont., Canada M5G 1X8
EDRS PRICE	MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS	Child Care; *Group Counseling; Interaction Process Analysis; Intervention; *Nurses; *Parent Child Relationship; *Parents; *Premature Infants; Program Evaluation; Research Projects; *Self Help Programs

ABSTRACT

A preventive intervention program based on self-help groups for parents reinforced by the involvement of veteran parents, those who had a premature infant during the past 12 months, and professionals to provide support and information was evaluated. Sets of randomly selected parents (N=35) met weekly in a small group of four to six couples during the first six months of their premature infant's life with the veteran mother and an experienced neonatal nurse. Other couples (N=35) receiving routine care served as a control group. Group parents exhibited a very positive response and high attendance. Group and control parents were compared on: (1) number and duration of hospital visits and telephone calls to the nursery; (2) a psychiatric interview assessing parenting ability; (3) objective ratings and parental attitudes towards hospitalization and their caretaking role; and (4) direct observation of parents and infants during parental nursery visits and during the first three months at home. Preliminary results indicate that group parents make more hospital visits, call to inquire about their infants more, and are more comfortable in their caretaking role. (Author)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED165077

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

K Minde

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC) AND USERS OF THE ERIC SYSTEM."

SELF-HELP GROUPS IN A PREMATURE NURSERY - A CONTROLLED EVALUATION

K. Minde, M.D., F.R.C.P.(C),
N. Shosenberg, B.Sc.N., P. Marton, Ph.D.
B. Hines, B.Sc., J. Shanoff, M.A.

From The Department of Psychiatry,
The Hospital for Sick Children and the
University of Toronto.

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

The recent psychological and psychiatric literature indicates that an increasing number of health professionals consider community based self-help groups to provide an important addition or alternative to the traditional professional care of medical as well as psychiatric conditions[1-7]. One reason for the interest in these groups is their immense increase during the past 20 years. Presently there are more than 300 registered self-help groups in the U.S. versus less than 200 in 1955, with AA alone claiming 350,000 members, cerebral palsy associations 100,000 and muscular dystrophy associations more than 500,000 members in 1970[6]. Yet despite the general endorsement of this movement by the public and various professionals there have been no methodologically sound published reports which have evaluated the efficacy of such self-help groups.

Factors which may be responsible for the difficulties in doing a proper evaluation of such groups are:

a) Self-help groups vary immensely in type and structure and investigators have not yet come up with a generally acceptable classification. For example, Katz and Bender[6] distinguish between groups whose focus is "outer" (towards the environment) or "inner

Presented in part at the 1978 Annual Meeting of the American Orthopsychiatric Association Meeting in San Francisco. Research was supported by Grant No. 606-1360-44A1 from Health & Welfare Canada and the Laidlaw Foundation.

Address for reprints: (K.M.) Department of Psychiatry, The Hospital for Sick Children, 555 University Avenue, Toronto, Ont. Canada. M5G 1X8.

CG 013175

directed" (towards the individual). Other authors[8] distinguish groups which aim at conduct reorganization (e.g. AA, or Synanon); sharing of a common stressful predicament (e.g. Parents Anonymous); self-actualization (T groups); and fighting discrimination (e.g. Gay groups). It is obvious that no single type of evaluation procedure would be appropriate for such a range of groups. Moreover, even within outwardly identical groups such as AA, wide variations in format and philosophy have been reported[9].

b) Self-help groups often have been founded in response to the perceived abuses and/or ineffectual working of professionals[2]. The process of a scientifically sound evaluation, however, implies the utilization of measures developed and accepted by professionals and for this reason is often resented by both the leaders and members of these groups.

Given these difficulties it seems that a requisite first step in evaluating the effects of self-help groups is to specify the characteristics as well as the aims of the groups under investigation. Second, it is important to find relevant measures of effectiveness for the groups in question. This in turn will usually require the participation of professionally trained evaluators and their acceptance by the group members. The present study is an attempt to meet these criteria by describing parental self-help groups in a premature nursery and showing their effect on a number of qualitative and quantitative parental caretaking characteristics.

METHOD

The study had 34 very small premature infants and their parents as subjects and was carried out in the premature nursery of The Hospital for Sick Children in Toronto The selection of subjects took place in

two stages.

1. Parents: To be included in the study the parents were required to:
   a. live within 15 miles of The Hospital for Sick Children;
   b. speak English;
   c. intend to keep the baby.

2. Infants: All infants whose parents met the above criteria were included in the study if they met the following additional criteria:
   a. had a birthweight below 1501 grams;
   b. had no physical abnormalities;
   c. be a singleton birth;
   d. at age 72 hours had an absence of complications seriously compromising their chances of survival and/or normal cerebral functioning (e.g. intra-cranial haemorrhage or convulsions).

Once the infant and his family met the inclusion criteria and informed consent was obtained from the paediatrician and the family, four infants were alternately assigned to the self-help care programme (experimental group) or the routine care programme (control group). Two families refused to participate in the study, leaving us with a total of 16 control and 16 experimental families.

Procedure:

Control group: 72 hours after birth the parents of each control infant were contacted and asked whether they would permit us to regularly observe their infant in the nursery alone and during their hospital visits. Observations of the infant alone were made twice weekly for 40 minutes each. The observations consisted of continuous recordings of 12 infant behaviours. These behaviours were: eyes open; scanning; arm, leg, hand-to-mouth and mouth movement; smiling, crying, grimacing, vocalizing and yawning.

Characteristics of parent-child interactions were observed during parental visits in the nursery and during home visits one, two and three months after discharge from hospital. During these observations both the 12 infant behaviours and ten caretaker categories (looking and looking en face; smiling; instrumental and non-instrumental touch; vocalizing to infant and to others; holding; feeding; and standing less than three feet from infant) were recorded. Our technique of direct parent-child observations and its validity and reliability have been described in two previous publications[10-11].

Four to five weeks after the initial contact each parent was given a semi-structured interview by a child psychiatrist (K.M.). This interview, lasting approximately 60 minutes, gathered information relating to the parents' subjective experience during the pregnancy, delivery and postpartum period and their personal background. It also clinically assessed their attitude towards their caretaking role.

At the time of the infant's discharge from hospital parents were interviewed again and their attitude towards the medical and non-medical care the infant had received in hospital, the amount of their interaction with other parents on the ward and their general caretaking competence were rated on seven scales. Each of these scales was scored from 1 (most unsatisfactory) to 5 (most satisfactory) making it possible to have a total score of 7-35. Each rating category had a clear operational definition and hence allowed for objective scoring despite its clinical connotation, (e.g. satisfaction with medical care given to infants could vary between "impersonal procedures, unnecessarily unpleasant, inadequate for problem and arbitrary" to "feels that personal care was given infant, all that was

possible was done, procedures were excellent").

Experimental Group: All parts of the procedure outlined for the control group also applied to the experimental group parents. In addition, parents in this group were invited to meet with the group co-ordinator (N.S.) during their first hospital visit. At this time the parents were told about the availability of the group and a mutually agreeable meeting time set. The co-ordinator was a senior nurse who had worked in the same neonatal unit and taught nursing students for some time and had an excellent rapport with all the staff of the unit. She also had some previous experience in conducting prenatal groups but had never been involved in work with parents of premature infants.

Structure and Objectives of Group Meetings

Groups met once weekly for 90 - 120 minutes and consisted of up to ten parents; three to four study families and one to two "filler" families. The latter were parents who did not fulfill all the criteria of our study (e.g. lived more than 15 miles from the hospital) but were asked to join the group to make it bigger because it was at times difficult to find more than three infants meeting all our study criteria who were born in close enough succession to start a group together. In addition to the participants and the co-ordinator, each group had a "veteran mother". This woman had had a similar small baby in our nursery during the previous 12-15 months and was known to us personally for her general sensitivity and integrity. The "veteran" was seen as the official animator of the group. Groups met for 7-12 weeks. There were five groups included in the present study. While the group co-ordinator did not at any time impose herself on any of the parents, she was nevertheless available to all the families at any time and in fact talked to virtually all the mothers and fathers in between group meetings.

The initial objective of the group was to provide parents with a forum within which they could share and learn to cope with the stresses associated with having a very small premature infant. We also hoped to assist the parents in learning how to cope with the highly technical routines and procedures employed on the ward and how to deal with the approximately 170 different nurses working in this 65 bed intensive and post-intensive care neonatal unit. Finally we hoped to help the parents to get adequate information from the appropriate medical person, to recognize and meet the present and future needs of their particular infant and to utilize supportive community resources.

In practice this meant that during the three to five initial meetings the parents talked primarily about their intense feelings of depression, fear and guilt about having given birth to such a small baby. Their relief about "not being alone in such a state" was usually quite dramatic and led to a great feeling of intimacy among group members and the veteran mother. Although not documented by empirical data we felt that only after these feelings had been shared was it possible for the parents to begin to comprehend and understand the implications of topics related to the treatment and care of premature infants such as the meaning of positive and negative pressure ventilators, oxygen levels, respiratory monitor or tube feedings. During later group meetings specific resource people were available to speak on infant stimulation, our hospital's neonatal follow-up programme or the general philosophy of neonatal intensive care. Films and slides highlighting the developmental needs of premature infants were used liberally during all these presentations. In addition an attempt was made to help parents with concrete tasks

such as getting babysitters, a better apartment or improved unemployment benefits as the need arose.

RESULTS

Table 1 summarizes the background data for our sample. It indicates that the experimental and control groups were well matched on sociological and obstetrical variables but that the parents in the experimental group had given birth to a higher number of girls although this did not reach statistical significance ($\chi^2 = 1.42$, $p < .5$).

(Insert Table 1 about here)

The table also shows that we dealt with a generally lower class population, 50% of whom had lost from 1-7 babies during various previous pregnancies. This high percentage of mothers with past obstetrical difficulties in the present sample confirms data from our previous study[11].

The group attendance of the experimental families was very high. 50% of the parents attended all the sessions, 25% missed only one and the rest came to at least one-third of the group meetings. Parents who showed the highest degree of overt psychological and social pathology (i.e. had a husband in jail, were physically mistreated or showed symptoms of a major psychiatric disorder) had the lowest attendance. In three cases they attended their first group meeting only after they had four to six individual sessions with the group co-ordinator. It appeared as if these mothers required a certain amount of individual care before they could tolerate the presence and sharing with others.

Table 2 gives the number of visits per week the mothers made during their infants' hospitalization. It is clear that the mothers who attended the group visited the nursery significantly more often than did the control mothers.

(Insert Table 2 about here)

Table 3 shows the results of the interview at discharge. The table indicates that there were highly significant differences in five areas tapped by the questionnaire between the experimental and control mothers. The parental satisfaction with the nursing care their infant had received and the information they had obtained was only slightly higher in the experimental group.

(Insert Table 3 about here)

While the previous data give some indication about the wish of our mothers to be with their infant and about the effect of the group on expressed parental attitudes, they do not allow us to say anything about the actual behaviour of the mothers with the infants in the nursery and at home. Figures 1 and 2 attempt to give some indications of these variables.

(Insert Figures 1 and 2 about here)

The Figures indicate how much each of the five maternal behaviours which were independent of the infant's state of development and the presence of other visitors (i.e. looking; looking en face; talking to baby; smiling at baby; non-instrumental touching) occurred during one visit per week for the first five weeks of the infant's life in our total group of infants. We chose to analyse only one randomly selected visit per week in order to maintain a match in the post-conceptual ages between the experimental and control infants and also to permit a comparison between the groups which had different visiting frequencies. The analysis of one weekly visit also allowed us to see whether particular differences between the experimental and control groups first became evident at different times after the inception of the group meetings. T-tests were used for evaluating the differences between the weekly visits of the control and group mothers' behaviour.

Figures 1 and 2 show that initially both groups have a very similar rate of behaviour but that from three weeks onwards the mothers of the experimental group in general interacted more with their infants. However, only in touching during weeks 3, 4 and 5, looking en face during week 3 and vocalization to the infant during week 5 were the experimental mothers significantly more active than the control mothers.

DISCUSSION

The data clearly indicate that mothers of premature infants who have the opportunity to meet with each other with guidance from an experienced nurse counsellor and a veteran mother for 7-12 weeks visit their infants more frequently, interact more with them during visits and feel more competent about their general caretaking role than mothers who do not attend such group meetings.

The first question is whether these results are valid. The number of maternal hospital visits were recorded by the clerk of the neonatal unit and were taken from a book all parents have to sign before entering the ward. Since the clerk did not know whether a particular mother participated in the group discussions, the visiting data can be accepted as a valid estimate of parental visiting patterns. The discharge ratings were obtained by one of the authors (P.M.) who was also an observer during the maternal visits. While he was never associated with the group meetings, he often knew whether the woman in question had been a"group" or a "control" mother. Hence some bias of the results of the parental attitude scale theoretically cannot be ruled out. Our attempt to combat such bias consisted of clearly specifying definitions of any possible answer the parents could give to each question or item. This method of rendering clinical data objective has been found useful in the

deployment of other attitude scales used in psychiatric practice[12]. The lack of significant differences between the groups on the items denoting the satisfaction with nursing care given to their infants and the obtained information is probably related to the generally high satisfaction both groups showed in these areas and would support the notion that our assessments were fairly objective. Finally, the group differences in some actual behaviours shown by the mothers toward their infants imply that behavioural changes went beyond an expressed attitude and thus strengthen our general findings. It is especially interesting to see that non-instrumental touching (i.e. stroking, kissing or general touching of an infant, which was not associated with basic caretaking needs such as diapering), showed the most consistently significant difference in favour of the experimental mothers. This may indicate that the group meetings did ease the mothers' hesitation to touch their infants, especially since the increase in touching occurred only from week 3 onward, i.e. after the mothers had attended at least two group meetings. The sudden increase in the amount of looking en face behaviour shown by the experimental group during week 3 may possibly be a chance finding although the graph also allows for the possibility that the experimental mothers simply got a head start vis-a-vis their control peers, since the control mothers gradually caught up with them over the following three weeks. Whether the increasing amount of vocalization shown by the experimental mothers during week 4 and especially during week 5 is a late effect of the group meetings or a simple chance finding would require the analysis of later nursery visits. Such an analysis becomes difficult, however, because a certain proportion of our infants by this time are discharged to their local hospitals or can be held outside the incubator, giving rise to different maternal behaviours such as holding or feeding which were not included in this analysis.

The next question is whether the changes in visiting patterns, parental attitudes and behaviour during visits associated with the group meetings have long-term consequences. This is important for a variety of reasons. Group meetings could be beneficial primarily because they attenuate the psychological pain associated with the crisis of having a premature infant. In this case we would expect them to have no long-term effect on the parenting style of our mothers. If, however, as Klaus and his group suggest, there exists a "critical period" during which contact between the mother and her infant has implications for their later relationships, such group meetings may indeed be highly relevant for the later development of these children. Data from other studies suggest that the number of visits alone are predictive of some later maternal interactive behaviours and that mothers who visit frequently have infants who have superior speech development two years later[13-16]. Our own group in a previous investigation has also shown that the amount of maternal behaviour in the nursery is correlated with the amount of activity a mother shows with her infant three months after discharge from hospital[11]. On the other hand, data reporting on the grief process of recent widows indicate that while group meetings helped these women in coping with the stress of losing a husband, most women had passed through this crisis within two years after the death of their husbands even without intervention[7].

The final question raised by this paper is the degree to which the observed changes in the experimental group are related to the self-help aspect of the group meetings and the multiple individual encounters each group parent had with the group co-ordinator and other professionals on the ward. This is all the more important since our groups, which could best be classified as groups whose members share a common stressful

predicament, violated a number of premises normally associated with some types of self-help groups[8]. For example, our parents were asked to participate in the group meetings and did not join spontaneously. The co-ordinator, while staying in the background during actual discussions, was always present at meetings, organized refreshments and educational materials and was instrumental in inviting various resource people to address the group. She also spent a great deal of time with some mothers who were acutely disturbed by the day-to-day events of their babies, and in this respect undoubtedly fulfilled a truly therapeutic role.

It is not clear from the data presented to what extent this individualized approach, with its associated practical assistance to specific parents and the personality of the group co-ordinator, contributed to the results reported. However, from a clinical and ethical point of view, we could not overlook individual needs, especially of our poor families. Many of these parents needed, as Durman[9] has pointed out in his discussion on the role of self-help groups, concrete help in addition to psychological relief. While these issues obviously defy a methodologically pure research design, clinically we were nevertheless consistently impressed with the tremendous need all our families had to share their experience with each other. They invariably went through a severe crisis following the birth of their small infant and expressed an enormous relief in being able to talk about it.

In summary then we feel that the present results give a correct indication of the short-term benefits which group meetings with or without individual assistance can give the parents of small premature infants. A more detailed analysis of our data looking at the type of families which benefit most or least from such a programme and the

degree to which maternal behavioural changes persist beyond the first weeks of life will be reported in the future.

ACKNOWLEDGMENTS

This work could not have been done without the consistent co-operation and help of Dr P. Swyer, Director of the Neonatal Unit, Dr G. Chance, Mrs M. Bracht, Mrs S. Blacha, all the staff of wards 7F and 7G as well as our parents.

REFERENCES

1. McGee, T., and Wexler, S.
   The evolution of municipally operated, community based mental health services.
   Community Mental Health Journal, 8:303-312, 1972.

2. Dumont, M.
   Self-help treatment programs.
   Am. J. Psychiat.131:631-635, 1974.

3. Caplan, G.
   Support systems and community mental health.
   Behavioural Publications, New York, pp. 1-40, 1974.

4, Borman, L.D. (Ed).
   Explorations in self-help and mutual aid.
   Evanston, Ill., Center for Urban Affairs, Northwestern Univers. pp. 24-45, 1975.

5. Powell, L.F.
   The use of self-help groups as supportive reference communities.
   Am. J. Orthopsychiat.45:756-764, 1975.

6. Katz, A.H., Bender, E.I.
   Self-help groups in Western society: history and perceptives.
   J. of Appl.Behav.Science,12:265-282, 1976.

7. Vachon, M.L.S., Freedman, K., Formo, A., Rogers, J., Lyall, W.A.L., Freeman, S.J.J.
   The final illness in cancer: the widow's perspective.
   Can.Med.Assoc.J. 117:1151-1154, 1977.

8. Levy, L.H.

Self-help groups: types and psychological processes.

J. of Appl. Behav.Sci.12:310-322, 1976.

9. Durman, E.C.

The role of self-help in service provision.

J. of Appl.Behav.Science,12:433-443,1976.

10. Celhoffer, L., Boukydis, C., Muir, E., Minde, K.

A portable computer compatible event recorder for observing behavior.

Beh. Res. Meth. Instrum. 9(5):442-446, 1977.

11. Minde, K., Trehub, S., Corter, C., Boukydis, C., Celhoofer,L., Marton, P.

Mother-child relationships in a premature nursery: an observational study.

Pediatrics,61(3):373-379.

12. Spitzer, R.L., Endicott, J.

Current and Past Psychopathology Scales.

New York Department of Mental Hygiene, New York. 1968.

13. Klaus, M.H., Jerauld, R., Kreger,N., McAlpine, W., Steffa, M., Kennell, J.H.

Maternal attachment: importance of the first post-partum days.

New Engl. J. Med.286:460-463, 1972.

14. Leiderman, P.H., Seashore, M.J.

Mother-infant neonatal separation: some delayed consequences.

In: Ciba Foundation Symposium 33. Parent-infant Interaction.

Assoc. Scientific Publ. Amsterdam, pp.213-239, 1974.

15. Ringler, M.M., Kennell, J.H., Jarvella, R., Navojosky, B.J., Klaus, M.H.
Mother-to-child speech at 2 years - effects of early post-natal contact.
J. Pediat. 86:141-144, 1975.

16. Ringler, N.M., Tauser, M.A., Klaus, M.H.
Mother's speech to her two year-old: its effect on speech and language comprehension at 5 years.
Pediat.Res.10:307, 1976.

TABLE 1

BACKGROUND DATA

	Experimental	Controls
INFANTS	N = 16	N = 16
Sex: Female	12	7
Male	4	9
Birthweight:		
Mean	1168 gms	1175 gms
S.D.	208	272
MOTHERS		
Marital status:		
Married	13	12
Single	3	4
Parity:		
Primipara	9	8
Multipara	7	8
Previous abortions:		
one	3	8
More than one	4	0
Lost infant <3 mos old	1	3
Socio-economic class:		
1 and 2	3	2
3	4	4
4 and 5	9	10

TABLE 2

MATERNAL NURSERY VISITS

GROUP	CONTROLS
N = 16	N = 16
Mean 5.2/week	Mean 2.7/week
S.D. .48	S.D. .26

$t = 2.63$

$p < .05$

TABLE 3

PARENTAL ATTITUDE AT TIME OF INFANT'S DISCHARGE

	Experimental N=16		Controls N=16			
	Mean	S.D.	Mean	S.D.	t	Significance[1]
Satisfaction with medical care	4.7	.58	4.2	.66	2.55	< .025
Satisfaction with nursing care	4.4	.73	3.9	.77	1.92	< .10
Satisfaction with information	4.2	.68	3.8	.83	1.63	< .10
Understanding of infant's condition	3.8	1.28	2.6	.73	3.29	< .01
Interaction with other parents	3.9	1.29	1.6	.96	5.78	< .001
Comfort with ability to care for baby at home	3.7	1.24	2.9	.68	2.31	< .05
Knowledge of community resources	3.7	1.24	2.4	.89	3.45	< .01
Total score	28.4	5.11	21.4	3.79	4.40	< .001

[1] Significance levels are for 2 tailed tests. df = 30

FIGURE 1

MATERNAL BEHAVIOR OBSERVED IN THE NURSERY

DURING ONE WEEKLY VISIT OVER FIVE WEEKS

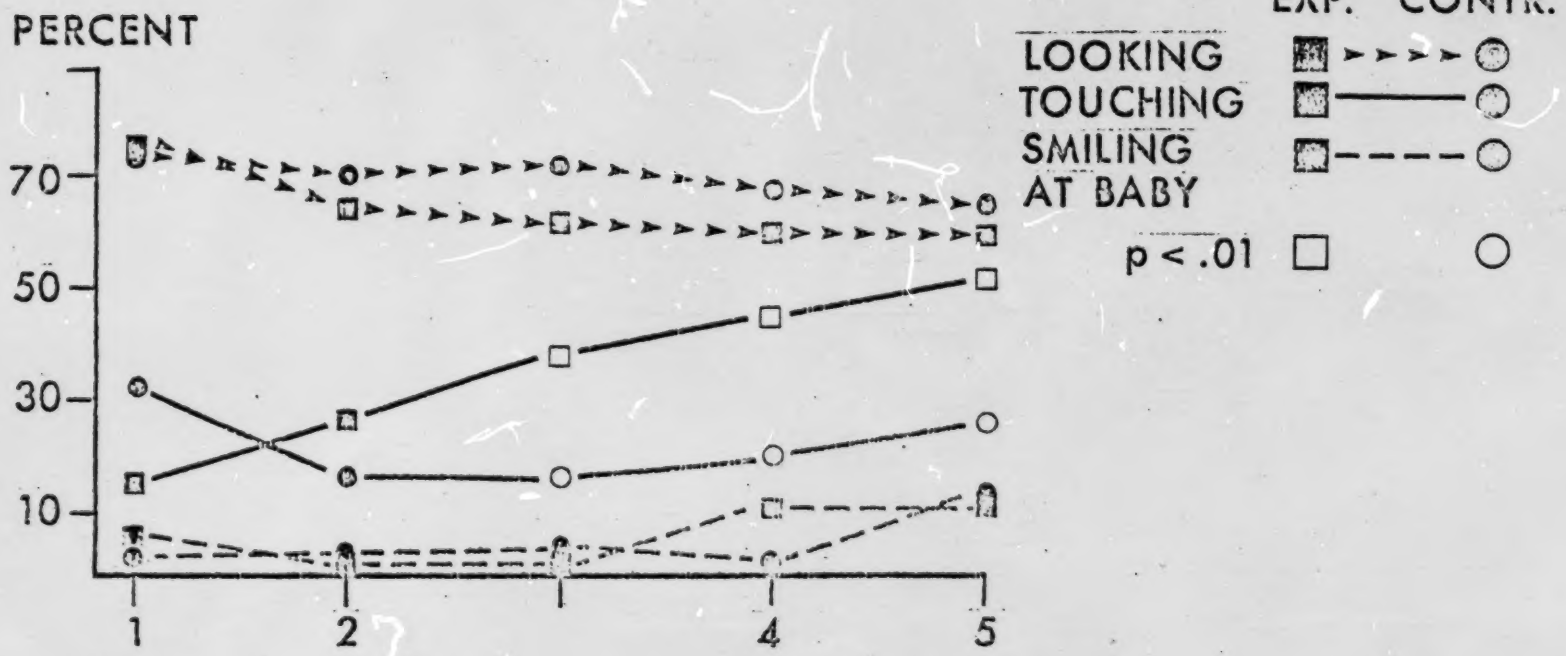
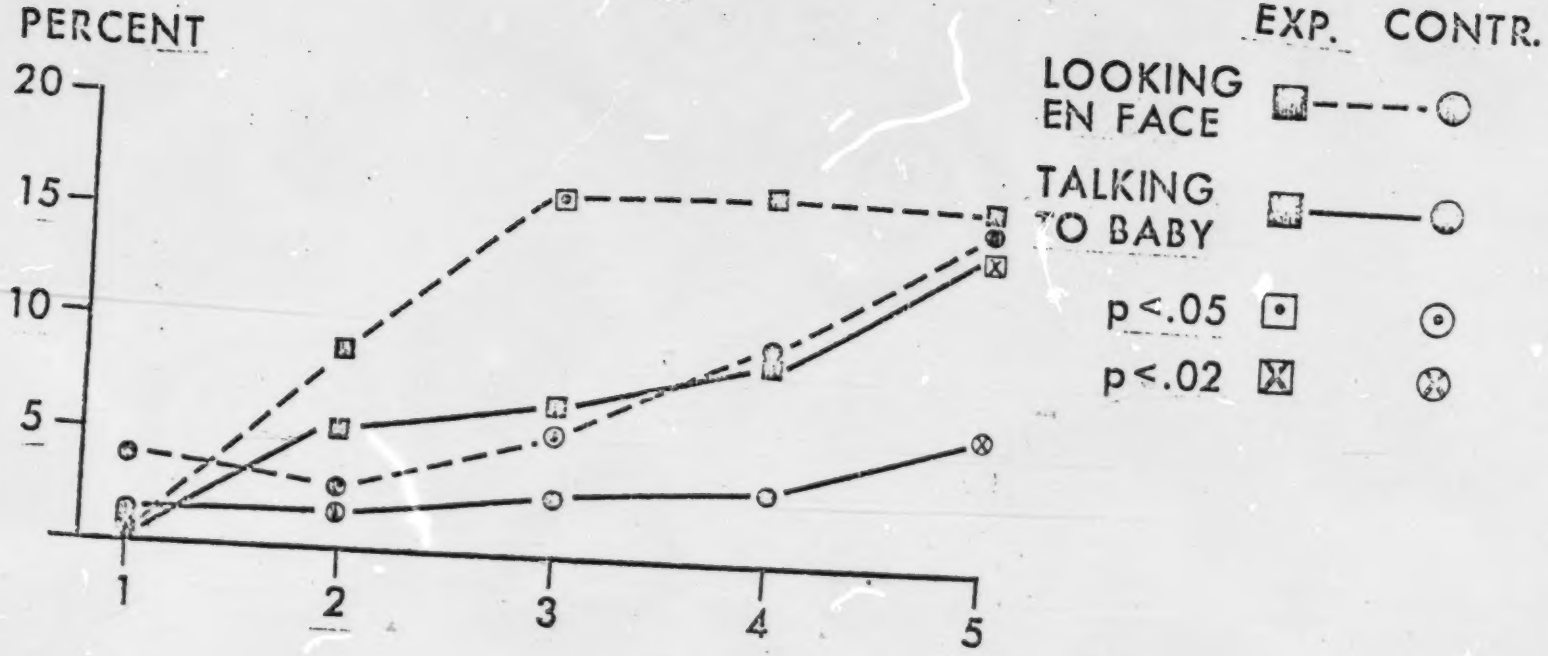

PERCENT
70
50
30
10
1
2
4
5
EXP. CONTR.
LOOKING
TOUCHING
SMILING AT BABY
p < .01

FIGURE 2

MATERNAL BEHAVIOR OBSERVED IN THE NURSERY
DURING ONE WEEKLY VISIT OVER FIVE WEEKS


PERCENT
20
15
10
5
1
2
3
4
5
EXP.
CONTR.
LOOKING EN FACE
TALKING TO BABY
p<.05
p<.02